

**ndss**  
national diabetes services scheme



# YOUTH TRANSITION SURVEY

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# Acknowledgements

Diabetes Australia would like to acknowledge and thank all members of the NDSS Diabetes in Youth Working Party for developing the survey, which include:

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The Social Research Centre as authors of The Youth Transition Survey Report.

The 1,436 young adults who took part in the Youth Transition Survey.

ISBN 978-0-6465815-0-7

Suggested citation: Diabetes Australia LTD. Youth transition survey. Diabetes Australia: Canberra, ACT

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*The views expressed are those of the authors and do not necessarily reflect those of the Australian Government*



## Message from Prof. Susan Sawyer

As children mature through adolescence into young adulthood they experience many different transitions around education and work, peer and family relationships, and social roles. The 14,755 young Australians aged 14–24 who live with type 1 and type 2 diabetes face the additional challenge of making a major health transition during these years. This involves changing roles and responsibilities around diabetes care within families, as well as greater independence and autonomy around how young people engage with their health professionals. Part of this process also generally involves the physical transfer of health care from a specialist paediatric or adolescent setting to an adult health care setting.

There is evidence that a number of adolescents and young adults struggle to engage with health services across these years, and indeed, risk dropping out of health care altogether at this time - with potentially devastating consequences for their health. As a result, Diabetes Australia has embarked upon gaining a broader understanding of the transition process from the people whom it affects most - young people who are currently involved in the transition process, whether managed by paediatric, adolescent, young adult or adult services. It includes young people who have 'fallen through the cracks' and are not currently engaged in any health services.

I am pleased to present The Youth Transition Survey to you. This survey of Victorian and Tasmanian young people aged 14–24 years with type 1 and type 2 diabetes has been undertaken through the National Diabetes Services Scheme (NDSS), an initiative of the Australian Government, which is administered by Diabetes Australia. The survey was developed with the goal of identifying the issues experienced by young people around transitional health care as well as exploring what resources may be helpful for young people at this time. It is the largest most comprehensive survey of its type in Australia, and had the advantage of recruiting young people from many different clinics across the two States.

On behalf of NDSS Diabetes in Youth Working Party, I would like to thank the 1,467 young people who took part in the Youth Transition Survey. Their participation has provided a greater understanding of what is needed to optimise their health care at this important time. It is hoped that these data will assist to empower young people by providing them with the knowledge, support and ultimately the type of health care system that will best support them make a successful health and life transition.

**Professor Susan Sawyer**  
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**January 2012**

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# Executive Summary

## Overview

This report presents key findings from a survey conducted by the Social Research Centre to provide baseline evidence for Diabetes Australia about the issues faced by young people with diabetes as they move from paediatric to adult health care.

The survey was conducted using a multi-method design where respondents had the option to participate online or via Computer Aided Telephone Interviewing (CATI). The in-scope population for the survey was young people aged 14 to 24 years with type 1 or type 2 diabetes currently residing in Victoria or Tasmania. The research was conducted between 29 June and 24 July 2011 and 1,436 young people participated in the survey.

## Profile of young people with diabetes

Key findings:

- Ninety-seven percent of 14 to 17 year olds and 93 percent of 18 to 24 year olds who participated in the survey indicated that they had type 1 diabetes.
- Age of first diagnosis was most commonly between ten and 15 years (36%).
- As would be expected, the majority of young people aged 14 to 17 were living at home with their parents (79%) and 14 percent were in a single parent household.
- Two thirds (69%) of the 18 to 24 year olds were living in a couple or single parent home situation, and in almost all instances (97%) this was as a child of the household.
- Less than half of the 18 to 24 year olds (42%) reported that they were attending a diabetes clinic, whereas 71 percent of the 14 to 17 years olds indicated that this was the case. Respondents most frequently reported that they used insulin injections to manage their diabetes (70%).

## Use of health care professionals

An examination of patterns of health care use identified three groups of young people; appropriately engaged, tenuously engaged and disengaged.

- Those who are appropriately engaged with health care practitioners (68%) have seen both a general practitioner and an endocrinologist in the past six months.
- Tenuously engaged young people (24%) appeared to have a more irregular pattern of contact with their health care professionals. For example, nine percent of respondents had seen an endocrinologist in the last six months but hadn't seen a general practitioner within the last 12 months.

- Of the 8 percent who seemed to be disengaged from their health care professionals, 52 percent were aged 14 to 17 and 48 percent were 18 to 24 years old. Given that most of the 14 to 17 year olds attend medical appointments with a parent or guardian and, as such, likely to be attending appointments on a regular basis, this observation suggests that these younger people may not necessarily understand who they are seeing and the role that they play in the care of their diabetes.

## Information about care and management

Key findings:

- Eighty six percent of those aged 18 to 24 reported discussions with their health care practitioners about alcohol and diabetes and three quarters (75%) had discussed smoking and diabetes.
- Fifty one percent of the young people said they had discussed mental health issues with their health care professionals.
- Of the females who responded to the survey, only 69 percent of 18 to 24 year olds and 42 percent of 14 to 17 year olds indicated that they had spoken to a health professional about pregnancy and diabetes.
- Sixty percent of females expressed an interest in finding out more about pregnancy and diabetes.
- The least frequently discussed topic with health care professionals was the restriction of insulin to lose weight (38%).

## Parental involvement & independence

Key findings:

- Parents or guardians were regarded by young people as the most important person when it comes to their diabetes care, with 73 percent of 14 to 17 year olds and 54 percent of 18 to 24 year olds.
- Approximately nine out of ten (91%) 14 to 17 year olds said that their parents or guardians were responsible for booking their medical appointments whereas 73 percent of those aged 18 to 24 indicated that they were responsible for making the appointments.
- Parents or guardians of 14 to 17 year olds typically ensure that they get to their medical appointments (95%) whereas 76 percent of 18 to 24 year olds get to their medical appointments by themselves.
- The person most likely to accompany a young person with diabetes to a medical appointment was a parent or guardian with 99 percent of 14 to 17 year olds and 89 percent of 18 to 24 year olds indicating that this was the case.
- Nine percent of respondents aged 18 to 24 reported that their spouse or partner came to their medical appointments with them.

## Transitioning to an adult service

Key findings:

- Almost half of the 18 to 24 year olds (49%) and 71 percent of the 14 to 17 year olds had never discussed transitioning to an adult service with a health care professional. This finding is somewhat surprising as almost every young person surveyed indicated that services were provided by a diabetes nurse educator at their clinic.
- Given that any of 18 to 24 year olds could potentially make an immediate transition to an adult service, it would be expected that more than the reported 37 percent should have discussed the process with a health professional in the last 12 months.
- Despite the fact that 37 percent of young people had discussed the transition to an adult service with a health professional, only 12 percent of 14 to 17 year olds and 26 percent of 18 to 24 year olds knew which adult service they were going to transfer to.
- Thirty nine percent of 18 to 24 year olds suggested that they were completely ready to transfer to an adult clinic however the data does not indicate why they had not yet made this transition.
- Twenty three percent of young people who were currently attending a paediatric or YADS clinic said that they were worried about making the transition to an adult service.
- Respondents aged 18 to 24 were most concerned about having new doctors (36%) and the level of care that they would receive at the adult clinic (30%).
- Understandably, 14 to 17 year olds were most worried about becoming independent (29%), however, they also expressed concerns about new doctors (25%) and the support that they would receive (20%).
- When were asked what information Diabetes Australia or the NDSS could provide to assist young people to make the transition both 18 to 24 year olds (45%) and 14 to 17 year olds (31%) wanted to receive information about specialists in their area. There was also interest in information that would help them to understand what to expect from the transition.
- Of the 87 young people who transferred to an adult clinic from another clinic, 62 percent said that someone had helped them to prepare to make the change. Diabetes nurse educators were mentioned most often (35%) as supporting the transition process with endocrinologists (33%), general practitioners (27%) and family members (19%) also reported as having assisted the young person to make the transition.
- Diabetes camps and the NDSS were never offered as having assisted with the transition.

## Transition Liaison Coordinators

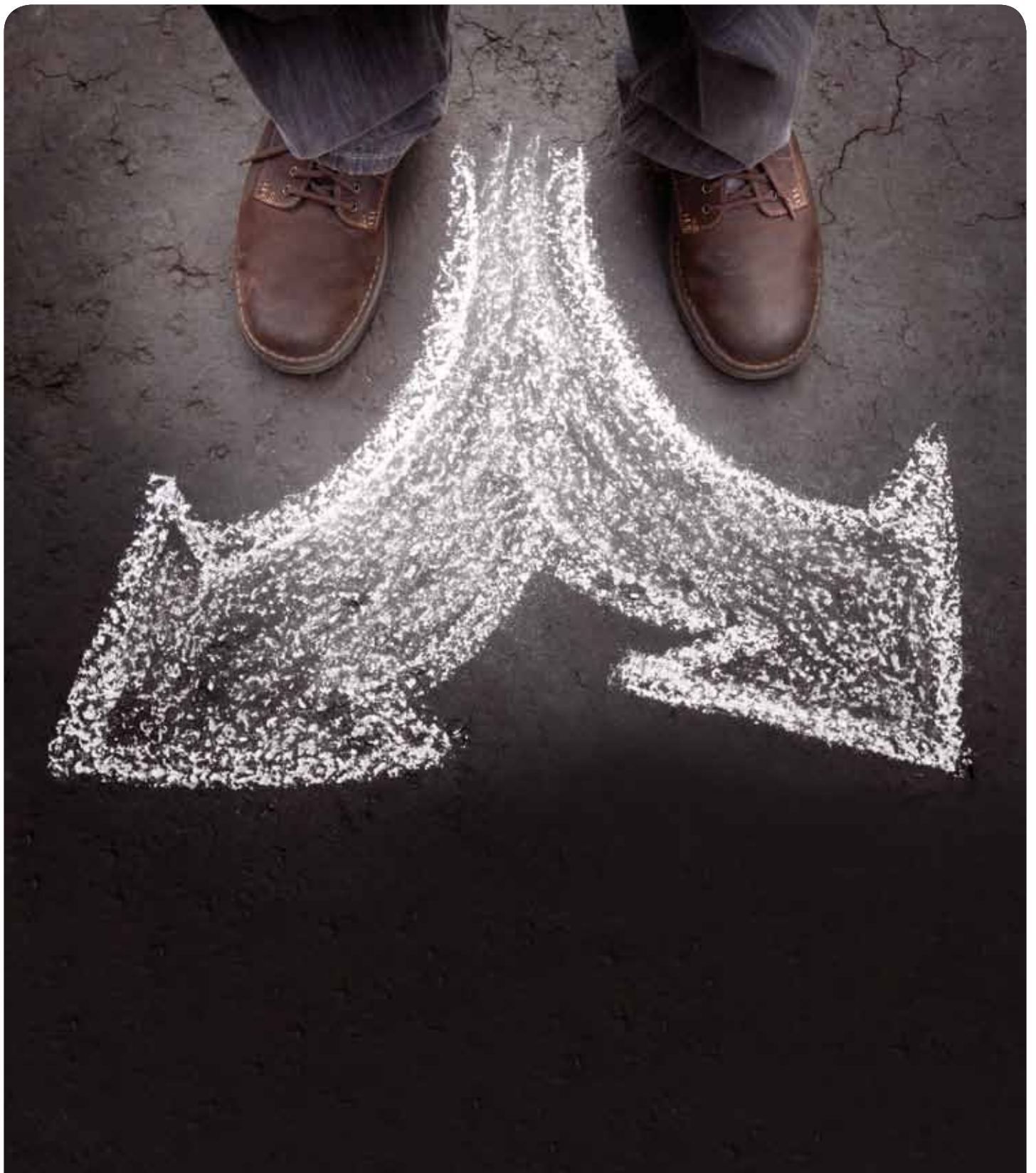
Young people were asked to consider the idea of a transition liaison coordinator and, in general, they were overwhelmingly positive about the concept.

- 91 percent indicated that they were positive or somewhat positive about this idea.
- Most respondents indicated that it was good to have someone there (36%) and others liked that they had someone to contact (19%).
- 16 percent indicated that a transition liaison coordinator was better for the process or that it represented a more personalised approach to providing support (14%).
- Of the 87 young people who were currently attending an adult clinic, just over half (52%) felt that a transition liaison coordinator might have made their transition to this new service easier.

## Young people disengaged from care

Three levels of disengagement from the health care system were observed in the data.

- The first level of disengagement was from receiving care from specific professionals. In this case, some young people reported that there were health care professionals that they had never seen and a number of these practitioners were vital to the effective management of their condition.
- The second level of disengagement was evident in those young people who indicated that they were either not currently attending or had never attended a clinic to support their care.
- The smallest group (16 respondents), but most serious level of disengagement, were young people who did not appear to be engaging with the health care system at all, other than to fulfil the most basic aspects of managing their condition.
- A better understanding of engagement and disengagement from care could support the targeting of prevention activities aimed at maintaining engagement and interventions to remediate disengagement.



“Almost half of the 18 to 24 year olds (49%) and 71 percent of the 14 to 17 year olds had never discussed transitioning to an adult service with a health care professional”



# 1. Introduction

## 1.1 Background

Transition, in the context of diabetes care, traditionally refers to the “purposeful, planned movement of adolescents and young adults...from child-centred to adult-orientated health care systems” (Blum et al., 1993: 570). The process involves both the physical transfer of an adolescent or young adult from one setting to the other, and the acquisition and practise of self-management skills and the shift of responsibility of care from parent to individual. Transition, therefore, is not only the physical transfer of an individual moving from a child or adolescent health setting to an adult health service, but also the environmental, emotional and psychological factors that are included in this process.

There are currently 14,755 people aged between 14 and 24 living with either type 1 or type 2 diabetes in Australia. Of these young people 3,642 reside in Victoria and 379 in Tasmania<sup>1</sup>. This represents the number of people who are currently going through transition, or have done so recently.

## 1.2 Overview

Diabetes Australia commissioned the Social Research Centre to undertake a multi-method study of young people aged 14 to 24 years who have type 1 or type 2 diabetes. Findings from this research will be used by Diabetes Australia to provide targeted services and support programs to young people with type 1 or type 2 diabetes. Through the NDSS National Development Program, the Youth Transition Survey aims to identify the issues young people with diabetes face as they move from paediatric to adult health care. This research explores a number of key themes including:

- current health care and use of health care professionals,
- independence and taking control of own diabetes care,
- attendance at a diabetes clinic,
- transition to adult services,
- payment for diabetes care products and services,
- communication issues and preferences, and
- attitudes towards Transition Liaison Coordinators.

The Youth Transition Survey commenced on 29 June 2011 and concluded on 24 July 2011. This report presents the findings of this research and is based on 1,436 interviews with young people who have diabetes.

Surveys were completed using Computer Assisted Telephone Interviewing (CATI) and an online data collection platform. Summary fieldwork statistics and methodological details have been provided to Diabetes Australia in a separate technical report<sup>2</sup>.

## 1.3 About the survey

The sample for the Youth Transition Survey was drawn from the National Diabetes Services Scheme (NDSS) registry, which is a voluntary and free registration open to all Australians with diabetes.

The sample consisted of young people between 14 and 24 years of age who were identified as having type 1 or type 2 diabetes and residing in Victoria or Tasmania. Exclusions made by the Social Research Centre (prior to commencing data collection) included records without a Victorian or Tasmanian postcode, records without a valid phone number and valid address, clients under the age of 18 without carer/parent contact information, respondents living in the same household (in these cases, one record was randomly chosen for exclusion); and clients identified as having “gestational” diabetes.

## 1.4 About this report

The main focus of this report is on describing the data collected by the survey. The body of the report is divided into eight main sections and the broad topic areas covered in these sections are as follows:

- section 2 provides basic profile information about young people with diabetes;
- section 3 examines use of health care professionals in managing diabetes care;
- section 4 reports parental involvement and the independence of young people in managing their care;
- section 5 explores the transition to an adult service both from the perspective of young people yet to make the transition and from the viewpoint of those who are currently receiving an adult service;
- section 6 looks at the information needs and interests of young people with diabetes;
- section 7 reports on views about the concept of a transition liaison coordinator; and
- section 8 identifies and explores issues related to young people who seem to be disengaged from care.

Where possible, results are displayed by age group to separate minors aged under 18 from the other respondents. For some survey items there is sufficient data to show the results according to whether or not the young person is attending a clinic. In those cases where the sample size is too small to support a robust analysis of the data, less than 50 responses, but where the issue is of key interest, frequencies have been reported in text rather than displaying proportions in a table.

<sup>1</sup> National Diabetes Services Scheme Registration statistics, November 2011.

<sup>2</sup> The Social Research Centre, Youth Transition Survey Technical Report, September 2011.

## 2. Profile of young people with diabetes

### 2.1 Demographic characteristics

The Youth Transition Survey was completed by 1, 436 young adults with diabetes aged 14 to 24 years.

Ninety seven percent of 14 to 17 year olds and 93 percent of 18 to 24 year olds who participated in the survey indicated that they had type 1 diabetes. Table 1 contains reported age of first diagnosis of condition. Age of first diagnosis was most commonly between ten and fifteen years (36%) with just over a quarter of respondents (27%) reporting that they were first diagnosed between five and ten years of age. Given that 18 percent of young people were diagnosed when they were more than 15 years of age, it is possible that a substantial proportion never attend a paediatric or Young Adults Diabetes Service (YADS) clinic because they were too old at the time of first diagnosis.

**Table 1** Age first diagnosed with diabetes

Age	%
Less than 1 year old	2
1 to less than 5 years old	17
5 to less than 10 years old	27
10 to less than 15 years old	36
15 to less than 20 years old	15
20 years or more	3
Unsure	0

Base: All respondents (n=1,436).

Table 2 profiles select demographic characteristics of the survey respondents (see Appendix 1 for a complete profile). Almost two thirds (62%) of the survey respondents were aged between 18 and 24 which is slightly lower than the 70 percent of young people in this age group that were on the NDSS register. Just over half of the respondents were male (54%) and eight percent resided in Tasmania.

**Table 2** Demographic characteristics of young people

Respondent characteristics	% of age group			Age group		
	14–17	18–24	Total	14–17	18–24	Total
<b>Sample</b>	<b>30</b>	<b>70</b>	<b>100</b>	<b>1,089</b>	<b>2,617</b>	<b>3,706</b>
<b>Respondents</b>	<b>38</b>	<b>62</b>	<b>100</b>	<b>544</b>	<b>892</b>	<b>1,436</b>
<b>Gender</b>						
Male	53	55	<b>54</b>	289	487	<b>776</b>
Female	47	45	<b>46</b>	255	405	<b>660</b>
<b>Location</b>						
Tasmania	10	7	<b>8</b>	54	66	<b>120</b>
Victoria	90	93	<b>92</b>	490	826	<b>1,316</b>
<b>Household type</b>						
A person living alone	0	4	<b>2</b>	0	33	<b>33</b>
A couple, one or more children at home	79	58	<b>66</b>	432	518	<b>950</b>
A single parent, one or more children at home	14	11	<b>12</b>	75	97	<b>172</b>
Non-related people sharing a house or apartment	0	9	<b>6</b>	1	78	<b>79</b>
A couple with no children	0	7	<b>5</b>	1	64	<b>65</b>
Some other type of household	6	11	<b>9</b>	34	99	<b>133</b>

As would be expected, the majority of young people aged 14 to 17 were living at home with their parents (79%) and 14 percent were in a single parent household. Older respondents, aged 18 to 24, were more likely than those who were younger to report that they were sharing a house (9%), were living as a couple with no children (7%) or in some other type of household (11%). It should also be noted that more than two thirds (69%) of the 18 to 24 year olds were living in a couple or single parent home situation, and in almost all instances (97%) this was as a child of the household.

## 2.2 Clinic attendance

Just over half (53%) of the respondents indicated that they were attending a diabetes clinic, however, there were quite dramatic differences between the two age groups, as shown in Table 3. Less than half of the 18 to 24 year olds (42%) reported that they were attending a diabetes clinic whereas 71 percent of the 14 to 17 years olds indicated that this was the case.

**Table 3 Attendance at a diabetes clinic**

	Age group %		
	14–17	18–24	Total
Yes	71	42	<b>53</b>
No	24	55	<b>44</b>
Unsure	5	3	<b>4</b>

Base: All respondents (14–17 year olds: n= 544; 18–24 year olds: n=892).

Table 4 shows that, as would be expected, younger people with diabetes were more likely to attend a paediatric clinic (53%) whereas those who were older reported attending a YADS clinic (52%). Just over a quarter of 18 to 24 year olds (27%) were already attending an adult clinic. Somewhat counterintuitively, four percent of 14 to 17 year olds were attending an adult clinic and 13 percent of 18 to 24 year olds indicated that they were receiving services from a paediatric clinic, however, it is possible that these patterns of attendance are a result of clinic availability in the locations where these young people were living. Twelve percent of respondents did not know what type of clinic they were currently attending.

**Table 4 Type of clinic attended**

Clinic type	Age group %		
	14–17	18–24	Total
Young Adult Diabetes Service (YADS)	29	52	41
Paediatric clinic	53	13	33
Adult clinic	4	27	15
Unsure	15	9	12

Base: Respondents attending a clinic (14–17 year olds: n= 384; 18–24 year olds: n=377).

If a respondent was attending a clinic, their attendance was quite recent with 90 percent reporting that they had been to the clinic at least once in the past six months. It can also be seen from Table 5 that while 18 to 24 year olds were slightly less likely than 14 to 17 year olds to have attended a clinic in the last three months (69% vs 76%) attendance within a six month period was similar across all age groups. Levels of disengagement with clinic services was also similar across both age groups with comparable levels of attendance reported in the last 12 months and more than 12 months ago.

**Table 5 Last time clinic was attended**

Period	Age group %		
	14–17	18–24	Total
In the last 3 months	76	69	72
In the last 6 months	15	20	18
In the last 12 months	5	6	5
More than 12 months ago	3	5	4
Unsure	1	0	0

Base: Respondents attending a clinic (14–17 year olds: n= 384; 18–24 year olds: n=377).

Table 6 shows the types of services reported to be available at each of the different types of clinics and which of these services respondents believed were offered outside business hours. A diabetes educator was available at almost all clinics (97%) and was also most frequently reported to be available outside normal business hours. YADS clinics seem to be very well resourced compared to other types of clinics with most offering key services both during and outside normal business hours. Those attending adult clinics were least likely to report that their clinic had a social worker (43%) or a pharmacy (44%) available to them.

## 2. Profile of young people with diabetes (continued)

**Table 6** Services available at clinics during normal and outside business hours by type of clinic

Respondents	Clinic type %				Total
	Adult	Paediatric	YADS	Unsure	
<b>Respondents</b>	<b>115</b>	<b>249</b>	<b>308</b>	<b>89</b>	<b>761</b>
<b>Available services</b>					
Diabetes Educator	92	97	98	96	97
Endocrinologist	87	78	91	74	84
Pathology	75	81	83	73	80
Social Worker	43	70	63	49	61
Pharmacy	44	56	63	53	56
<b>Available outside normal business hours</b>					
Diabetes Educator	49	56	57	44	54
Pharmacy	36	36	39	26	36
Social Worker	29	28	40	23	33
Endocrinologist	39	24	39	24	33
Pathology	24	21	23	19	22

Base: Respondents attending a clinic.

Older respondents were more likely to indicate that it would be much easier for them to use the services of their clinic if they were offered outside of business hours (see Table 7). Across all clinic types, 18 to 24 year olds reported that it would be much easier (39%) or a little easier (22%) to see health care professionals outside normal hours. Approximately a third of the respondents attending an adult clinic (36%) or a YADS clinic (33%) suggested that it would be much easier to use the relevant services outside business hours.

**Table 7** Easier to use clinic services if offered outside business hours

Respondents aged	Clinic type %				Total
	Adult	Paediatric	YADS	Unsure	
<b>Respondents aged 14–17</b>	<b>4</b>	<b>108</b>	<b>54</b>	<b>22</b>	<b>188</b>
Yes - much easier	0	21	19	9	19
Yes - a little easier	25	35	33	32	34
<b>Respondents aged 18–24</b>	<b>52</b>	<b>20</b>	<b>97</b>	<b>19</b>	<b>188</b>
Yes - much easier	39	30	41	37	39
Yes - a little easier	23	35	21	16	22
<b>All respondents</b>	<b>56</b>	<b>128</b>	<b>151</b>	<b>41</b>	<b>376</b>
Yes - much easier	36	23	33	22	29
Yes - a little easier	23	35	25	24	28

### 2.3 Diabetes management

Table 8 shows that respondents most frequently reported that they used insulin injections to manage their diabetes (70%). Young people aged 14 to 17 were more likely (32%) than those who were 18 to 24 (24%) to manage their diabetes using a insulin pump. Respondents who were 18 to 24 were also more likely (20%) than 14 to 17 year olds (13%) to report they used lifestyle factors as one of the methods they used to manage their diabetes.

**Table 8** Method of managing diabetes

Management methods	Age group %			Clinic attendance %		
	14–17	18–24	Total	Yes	No	Total
Respondents	544	892	1,436	761	624	1,385
Insulin injections	66	72	70	67	73	70
Insulin pump	32	24	27	*	24	27
Lifestyle factors	13	20	18	*	18	18
Something else	3	4	3	2	4	3

Base: All respondents (clinic attendance excludes 51 respondents who did not know if they attended a clinic).

Note: Multiple response question, respondents were able to select more than one management method.

As would be expected, nearly all (98%) of young people aged 14 to 17 reported that their parents or guardians mostly paid for their diabetes care prescriptions (see Table 9). Respondents who were 18 to 24 tended to pay for their prescriptions themselves (57%) although 41 percent indicated that their parents still covered the costs associated with their diabetes care.

**Table 9** Person who mostly pays for diabetes care prescriptions

Respondents	Age group %			*	Clinic attendance %		
	14–17	18–24	Total		Yes	No	Total
<b>Respondents</b>	<b>544</b>	<b>892</b>	<b>1,436</b>		<b>761</b>	<b>624</b>	<b>1,385</b>
Mostly your parents or guardian	98	41	62	*	72	49	62
Mostly you	2	57	36	*	26	49	36
Both myself and with someone else	<1	2	1		1	1	1
Partner	0	<1	<1		<1	<1	<1
Someone else	0	<1	<1		0	<1	<1
Unsure or refused	<1	<1	<1		<1	<1	<1

Base: All respondents (clinic attendance excludes 51 respondents who did not know if they attended a clinic).

Note: Columns may not add due to rounding.

Before participating in the survey, 92 percent of 18 to 24 year olds and 81 percent of those aged 14 to 17 had heard of the National Diabetes Service Scheme (NDSS). Eighty-eight percent indicated that they had purchased an NDSS subsidised product in the past and seven percent were unsure if the product that they had purchased were subsidised.

Table 10 shows that most respondents had purchased NDSS products very recently, with 81 percent reporting a purchase in the last three months and 11 percent in the last six months.

**Table 10** Last time NDSS products purchased

Period	Age group %		
	14–17	18–24	Total
In the last 3 months	83	80	81
In the last 6 months	10	12	11
In the last 12 months	2	4	3
More than 12 months ago	1	3	2
Unsure	4	1	2

Base: Respondents who had purchased NDSS products (14–17 year olds: n= 462; 18–24 year olds: n=805).

Thirteen percent of 18 to 24 year olds and five percent of those aged between 14 and 17 said that there had been one or more occasion in the last 12 months when they or their parents hadn't bought diabetes products because they cost too much. As shown in Table 11, the products that were most likely to not have been purchased due to cost were glucose meters or testing strips (73%) or insulin needles and related consumables (34%).

**Table 11** Products not purchased in the last 12 months due to cost

Products	Age group %			*	Clinic attendance %		
	14–17	18–24	Total		Yes	No	Total
<b>Respondents</b>	<b>26</b>	<b>119</b>	<b>145</b>		<b>72</b>	<b>70</b>	<b>142</b>
Glucose meter/testing strips	81	71	73		72	74	73
Insulin Needles/Consumables	23	37	34		32	37	34
Tablets	<1	2	1		1	1	1
Other	4	3	3		4	1	3
Unsure	<1	5	4		6	3	4

Note: Columns may not add due to rounding.

## 3. Use of health care professionals

All survey respondents were asked a detailed series of questions about their use of health care professionals, including the timing of their most recent visit with each health care professional, in order to assess their level of engagement with the system. Those who had seen health care professionals were also asked to indicate whether they had accessed these services through the public or the private health care system. Information was also sought regarding the frequency of HbA1c testing.

### 3.1 HbA1c testing

Table 12 shows that younger adolescents were significantly more likely than those aged 18 to 24 to have had their HbA1c tested in the last three months with 84 percent of 14 to 17 year olds and 64 percent of 18 to 24 year olds indicating that this was the case. Those who attended a clinic were also significantly more likely to have undergone an HbA1c test in the past three months (80%) than young people with diabetes who reported that they do not attend a clinic (61%). Of more concern are the eight percent of respondents who indicated that they had never had an HbA1c test. There does not appear to be an age difference for those who believed that they had never been tested however there was a trend towards young people who did not attend a clinic to report that they had never been tested. The small proportion of respondents (2%) who were unsure if they had ever received an HbA1c test may have been unfamiliar with the name of the test or, alternatively, this group may also have never been tested.

**Table 12** Timing of most recent HbA1c test

Last tested	Age group %			Clinic attendance %		
	14–17	18–24	Total	Yes	No	Total
<b>Respondents</b>	<b>544</b>	<b>892</b>	<b>1,436</b>	<b>761</b>	<b>624</b>	<b>1,385</b>
In the last 3 months	84	64	71	80	61	72
In the last 6 months	11	22	18	14	21	17
In the last 12 months or longer	2	13	9	4	15	9
Never	1	0	1	0	1	1
Unsure or refused	3	1	2	1	1	1

Note: Columns may not add due to rounding.

### 3.2 Engagement with health care professionals

Seventy-nine percent of young people with diabetes saw an endocrinologist and 77 percent saw a general practitioner at least once in the past 12 months, as shown in Table 13. Seeing an endocrinologist did not appear to be related to age, with similar proportions in each age group seeing this health professional in the past year, but does seem to be linked to clinic attendance. Eighty-five percent of young people attending a clinic saw an endocrinologist in the past 12 months with less than three quarters (72%) of those not attending a clinic reporting that they had seen this health professional in the same time period.

Similar patterns of responses are evident across age groups and clinic attendance in relation to seeing a general practitioner in the past 12 months. Young people aged 18 to 24 (80%) and those who did not attend a clinic (82%) were more likely to have seen a general practitioner in the last year.

Overall, engagement with other health professionals that young people should be seeing at least once every 12 months, was comparatively low. Only 62 percent had seen an eye specialist in the last year and only 50 percent had seen a dietitian. Youth aged 18 to 24 seem to be more likely than those who are younger to have seen an eye specialist (65%) and younger people with diabetes appear to have had more recent contact with a dietitian (63%). Dietetic support also appears to be more likely to be accessed by those who attend a clinic (58%).

**Table 13 Engagement with health care professionals in the past 12 months**

Health care professionals	Age group %			Attended clinic %		
	14–17	18–24	Total	Yes	No	Total
<b>All respondents</b>	<b>544</b>	<b>892</b>	<b>1,436</b>	<b>761</b>	<b>624</b>	<b>1,385</b>
Endocrinologist	78	80	79	85	72	79
General Practitioner	71	80	77	73	82	77
Diabetes Nurse Educator	83	62	69	81	56	69
Eye specialist	57	65	62	63	61	62
Dietitian	63	42	50	58	39	50
Paediatrician or physician	57	33	42	50	33	42
Dentist	41	38	39	37	41	39
Mental health professional	30	28	29	31	26	29
Podiatrist	26	12	17	23	11	18
Alternate therapist	4	5	5	5	4	5

Note: Multiple response question, respondents were able to select more than one health care professional.

A detailed breakdown of health professional usage in the last three, six and 12 months can be found in Appendix 2.

Table 14 examines the patterns of engagement with health care practitioners and identifies three groups of young people. Those who are appropriately engaged with health care practitioners (68%) have seen both a general practitioner and an endocrinologist in the past six months. Twenty-six percent have seen both professionals in the last three months.

**Table 14 Engagement with health care professionals**

Engagement with health care professionals	%
Both in the last 3 months	26
Both in the last 6 months	22
General Practitioner in the last 3 months & Endocrinologist in the last 6 months	9
Endocrinologist in the last 3 months & General Practitioner in the last 6 months	11
<b>Appropriately engaged</b>	<b>68</b>
General Practitioner in the last 6 months & Endocrinologist in the last 12 months	4
Endocrinologist in the last 6 months & General Practitioner in the last 12 months	3
General Practitioner in the last 6 months & Endocrinologist more than 12 months ago	8
Endocrinologist in the last 6 months & General Practitioner more than 12 months ago	9
<b>Tenuously engaged</b>	<b>24</b>
Both more than 12 months ago	4
Never seen either practitioner	5
<b>Disengaged</b>	<b>9</b>

Base: Respondents who had been assisted in their transition (n= 52).

Note: More than 12 months includes 'never' for the tenuously engaged youth. Columns may not add due to rounding.

Tenuously engaged young people (24%) appeared to have a more irregular pattern of contact with their health care professionals. For example, nine percent of respondents had seen an endocrinologist in the last six months but hadn't seen a general practitioner within the last 12 months. Nine percent of young people appeared to be clearly disengaged from their health care professionals. Four percent reported that they hadn't seen a general practitioner or an endocrinologist in the past 12 months. Five percent indicated that they had never seen either practitioner or were unsure if they had had contact with either health care profession more than 12 months ago.

## 3. Use of health care professionals (continued)

Of those who seemed to be disengaged from their health care professionals, 52 percent were aged 14 to 17 and 48 percent were 18 to 24 years old. Given that the majority of 14 to 17 year olds are attending their medical appointments with a parent or guardian and, as such, likely to be attending appointments on a regular basis, this finding suggests that these younger people do not necessarily understand who they are seeing and the role that they play in the care of their diabetes. This explanation for the apparent disengagement is also possibly applicable to the 18 to 24 year olds, however, with many of these people seeming to be less reliant on their parents to manage their care, they could also be intentionally disengaging from their health care professionals. Table 15 contains information about the individual who was regarded by the young person as being the most important in their diabetes care. Parents or guardians were clearly regarded as the most important person with 73 percent of 14 to 17 year olds and 54 percent of 18- 24 year olds.

**Table 15 Most important person in diabetes care**

Health care professionals	Age group			Attended clinic		
	14-17	18-24	Total	Yes	No	Total
<b>All respondents</b>	<b>544</b>	<b>892</b>	<b>1,436</b>	<b>761</b>	<b>624</b>	<b>1,385</b>
Parent or guardian	73	54	61	62	60	61
Endocrinologist	13	22	19	20	17	19
Diabetes nurse educator	13	10	10	14	6	11
General practitioner	6	11	10	9	10	9
Partner	0	9	6	4	9	6
Physician	5	2	3	4	2	3
Don't know	3	3	3	3	4	3
Dietitian	2	3	3	3	2	3
Other family member	2	2	2	2	2	2
Eye specialist	1	2	2	2	1	2
Friend	1	1	1	1	1	1
Podiatrist	1	1	1	1	1	1
Mental health professional	<1	1	1	1	<1	1

Note: Multiple response question, respondents were able to select more than one health care professional.

### 3.3 Use of health care systems

Young people who used specific health care professionals were asked to indicate whether they accessed their services through the public or the private health care system. It can be seen from Table 16 that most health care professionals were seen via the public health care system with the exception of dentists (41%) and alternate therapists (24%). Young people aged 14 to 17 were more likely to be unsure as to what type of health care system they had used to access services.

Diabetes nurse educators (79%) and dietitians (79%) were most frequently seen by all young people through the public health care system. Respondents aged 18 to 24 were more likely to see endocrinologists (35%) or podiatrists (41%) through the private system than those who were younger.



**Table 16** Health professionals seen by health care system

Health care professionals	18–24 %				All respondents %							
	Public	Private	Unsure	Number	Public	Private	Unsure	Number				
Diabetes nurse educator	79	13	8	444	78	17	5	545	<b>78</b>	<b>15</b>	<b>6</b>	<b>989</b>
Dietitian	79	14	7	341	76	19	5	367	<b>77</b>	<b>17</b>	<b>6</b>	<b>708</b>
General practitioner	61	27	12	379	66	31	4	701	<b>64</b>	<b>29</b>	<b>7</b>	<b>1,080</b>
Paediatrician or physician	63	21	17	308	63	27	11	290	<b>63</b>	<b>24</b>	<b>14</b>	<b>598</b>
Endocrinologist	68	20	12	416	59	35	6	705	<b>63</b>	<b>29</b>	<b>8</b>	<b>1,121</b>
Podiatrist	70	21	8	135	52	41	7	104	<b>62</b>	<b>30</b>	<b>8</b>	<b>239</b>
Mental health professional	52	37	11	163	59	38	4	249	<b>56</b>	<b>38</b>	<b>7</b>	<b>412</b>
Eye specialist	49	40	11	305	51	44	5	573	<b>50</b>	<b>42</b>	<b>7</b>	<b>878</b>
Dentist	42	49	8	217	40	57	3	333	<b>41</b>	<b>54</b>	<b>5</b>	<b>550</b>
Alternate therapist	25	50	25	20	23	70	6	47	<b>24</b>	<b>64</b>	<b>12</b>	<b>67</b>

## 4. Parental involvement & independence

Over half (55%) of 18 to 24 year olds said that they had their own Medicare card compared with only 16 percent of those aged 14 to 17. Twenty-seven percent of 14 to 17 year olds were unsure if they had their own Medicare card. In relation to Health Care Cards, 70 percent of those aged 14 to 17 reported that they had a Health Care Card compared with just under half (47%) of 18 to 24 year olds. Only 13 percent of 14 to 17 year olds were unsure if they had a Health Care Card. Understandably, independence will be limited if the young person does not have their own Medicare card and could also be curtailed if they are unable to access prescriptions at a reduced rate using a Health Care Card.

Table 17 shows, as would be expected that 91 percent of 14 to 17 year olds said that their parents or guardians were responsible for booking their medical appointments whereas 73 percent of those aged 18 to 24 indicated that they were responsible for making the appointments. Interestingly, just over a third of clinic attendees (36%) reported that they were personally responsible for appointment making.

[Table 17 Person responsible for booking medical appointments](#)

	Age group %			Attended clinic %		
	14–17	18–24	Total	Yes	No	Total
<b>All respondents</b>	<b>542</b>	<b>885</b>	<b>1,427</b>	<b>758</b>	<b>618</b>	<b>1,376</b>
Self	4	73	47	36	61	47
Parents or guardian	91	22	48	58	36	48
Someone else	5	5	5	6	3	5

Base: All respondents (clinic attendance excludes 51 respondents who did not know if they attended a clinic).

Table 18 clearly indicates that the parents or guardians of 14 to 17 year olds ensure that the young person gets to their medical appointments (95%) and 76 percent of 18 to 24 year olds get to their medical appointments by themselves. More than a third of clinic attenders (38%) usually get to their medical appointments by themselves.

[Table 18 How young people get to medical appointments](#)

	Age group %			Attended clinic %		
	14–17	18–24	Total	Yes	No	Total
<b>All respondents</b>	<b>542</b>	<b>885</b>	<b>1,427</b>	<b>758</b>	<b>618</b>	<b>1,376</b>
Parents or guardian	95	22	50	61	35	49
Self	4	76	49	38	63	49
Friend or relation other than parents	1	1	1	<1	1	1
Both myself and with my parents	>1	1	1	<1	1	1

Base: All respondents (clinic attendance excludes 51 respondents who did not know if they attended a clinic).

As was the case in relation to making medical appointments, younger respondents generally saw the doctor with someone else (81 percent of 14 to 17 year olds) and clinic attendees exhibited a greater tendency to see the doctor by themselves (45%), although the majority still saw a doctor at the clinic with someone else (53%) (see Table 19).

**Table 19** Accompanied visits to medical appointments

	Age group %			Attended clinic %		
	14–17	18–24	Total	Yes	No	Total
<b>All respondents</b>	<b>542</b>	<b>885</b>	<b>1,427</b>	<b>758</b>	<b>618</b>	<b>1,376</b>
Generally see doctor by myself	16	77	54	45	67	55
Usually with someone else	81	21	44	53	31	43
Some other situation	1	1	1	1	1	1
Both by myself and with someone else	1	1	1	1	1	1

Base: All respondents (clinic attendance excludes 51 respondents who did not know if they attended a clinic).

The person most likely to accompany a young person with diabetes to a medical appointment was a parent or guardian with 99 percent of 14 to 17 year olds and 89 percent of 18 to 24 year olds indicating that this was the case (See Table 20). Nine percent of respondents aged 18 to 24 reported that their spouse or partner came to their medical appointments with them.

**Table 20** Person attending medical appointments

	Age group %			Attended clinic %		
	14–17	18–24	Total	Yes	No	Total
<b>All respondents</b>	<b>439</b>	<b>185</b>	<b>624</b>	<b>404</b>	<b>192</b>	<b>596</b>
Parents or guardian	99	89	96	96	96	96
Spouse or partner	0	9	3	3	2	3
Other relative	1	1	1	1	1	1
Friend	0	1	<1	0	1	<1

Base: Accompanied respondents.



“Twenty three percent of young people who were currently attending a paediatric or YADS clinic said that they were worried about making the transition to an adult service”

## 5. Transitioning to an adult service

Young people with diabetes who were attending a paediatric or Young Adult Diabetes Service (YADS) clinic but had not yet transitioned to an adult clinic were asked about their preparation for and general opinions about the transition process. Respondents were also asked to comment on the type of information they might like to receive from Diabetes Australia or the NDSS about the transition process.

### 5.1 Preparation for the transition process

Table 21 shows the proportion of young people who had discussed taking an active role in their care with a health professional. Nearly half of the 14 to 17 year olds (49%) and 34 percent of the 18 to 24 year olds indicated that they had never discussed their role in taking care of their diabetes with a health professional. Similar proportions of 14 to 17 year olds (46%) and 18 to 24 year olds (44%) had discussed taking an active role in their care with a health professional in the last 12 months.

**Table 21** Discussed taking an active role in care with a health professional

Clinic type	Age group %		
	14–17	18–24	Total
Yes – in the last 12 months	46	44	45
Yes – more than 12 months ago	4	18	10
No / never	49	34	43
Unsure	2	4	3

Base: Respondents attending a paediatric or YADS clinic (14–17 year olds: n= 313; 18–24 year olds: n=244).

Almost half of the 18 to 24 year olds (49%) and 71 percent of the 14 to 17 year olds had never discussed transitioning to an adult service with a health care professional, as can be seen in Table 22. This finding is somewhat surprising as almost every young person surveyed indicated that services were provided by a diabetes nurse educator at their clinic. Given that any of the 18 to 24 year olds could potentially make an immediate transition to an adult service, it would be expected that more than the reported 37 percent should have discussed the process with a health professional in the last 12 months.

**Table 22** Discussed the transition to an adult service with a health professional

Clinic type	Age group %		
	14–17	18–24	Total
Yes – in the last 12 months	25	37	31
Yes – more than 12 months ago	2	12	6
No / never	71	49	61
Unsure	3	2	2

Base: Respondents attending a paediatric or YADS clinic (14–17 year olds: n= 313; 18–24 year olds: n=244).

Despite the fact that 37 percent of young people had discussed the transition to an adult service with a health professional, only 12 percent of 14 to 17 year olds and 26 percent of 18 to 24 year olds knew which adult service they were going to transfer to. It is also concerning that 42 percent of 14 to 17 year olds and 43 percent of 18 to 24 year olds were unsure at what age they were expected to transfer to an adult service. Of those who offered an age at which they would be expected to transfer, 14 to 17 year olds believed, on average, that they would transfer at 18 years of age whereas 18 to 24 year olds reported, on average, that they would be expected to attend an adult clinic when they were 21.

Table 23 contains information about the perceived readiness of young people currently attending a paediatric or YADS clinic to transition to an adult service. Understandably, younger respondents were less likely than those aged 18 to 24 to feel that they were ready to transfer although, a substantial proportion of the older respondents felt that they were not ready (18%) or that they were unsure of their readiness (8%). Thirty nine percent of 18 to 24 year olds suggested that they were completely ready to transfer to an adult clinic however the data does not indicate why they had not yet made this transition.

## 5. Transitioning to an adult service (continued)

**Table 23** Readiness to transfer to an adult service

Clinic type	Age group %		Total
	14–17	18–24	
Yes – completely ready	12	39	24
Yes – somewhat ready	33	36	34
No – not ready	44	18	33
Unsure	11	8	9

Base: Respondents attending a paediatric or YADS clinic (14–17 year olds: n= 313; 18–24 year olds: n=244).

### 5.2 Transition support

Twenty-three percent of young people who were currently attending a paediatric or YADS clinic said that they were worried about making the transition to an adult service. Respondents aged 18 to 24 were most concerned about having new doctors (36%) and the level of care that they would receive at the adult clinic (30%) (see Table 24). Understandably, 14 to 17 year olds were most worried about becoming independent (29%), however, they also expressed concerns about new doctors (25%) and the support that they would receive (20%). Those aged 18 to 24 also expressed concerns about a perceived lack of information (17%) whereas younger respondents, 14 to 17 year olds, indicated that they had financial concerns (12%).

**Table 24** Worries about transitioning to an adult service

Issue of concern	Age group %		Total
	14–17	18–24	
New doctors	25	36	30
Level of care and support	20	30	25
Becoming independent	29	9	19
Lack of information	8	17	12
Financial concerns	12	2	7
Other	9	8	9

Base: Respondents concerned about making the transition to an adult clinic (14–17 year olds: n= 65; 18–24 year olds: n=64).

Table 25 shows the most preferred source of information about the transition to a new service. Most felt that they would prefer to receive this transition information from a health professional (44%). Thirty-five percent of young people aged 18 to 24 said that it made no difference who they got the information from and 28 percent of those aged 14 to 17 suggested that they would like to receive information from Diabetes Australia or the NDSS.

**Table 25** Preferred information source about the transition

Information source	Age group %		Total
	14–17	18–24	
Health professional	42	46	44
Makes no difference	21	35	27
Diabetes Australia or the NDSS	28	16	23
Unsure	4	2	3
Other	4	2	3

Base: Respondents attending a clinic (14–17 year olds: n= 313; 18–24 year olds: n=244).

Those who were still attending a paediatric or YADS clinic were asked what information Diabetes Australia or the NDSS could provide to assist young people to make the transition. Forty three percent of young people were unsure about what information could be provided however 57 percent made some suggestions about the type of information they would like to receive to help make the transition to an adult clinic (see Table 26). Both 18 to 24 year olds (45%) and 14 to 17 year olds (31%) wanted to receive information about specialists in their area. There was also interest in information that would help them to understand what to expect from the transition with 35 percent of those aged 14 to 17 and 27 percent of 18 to 24

year olds indicating that this was the case. Younger respondents were more interested in finding out about the differences between the services (23%) than 18 to 24 year olds (11%). Other transition-related information that was thought by respondents to be helpful included general information (14%), non-specific brochures (8%), when to make the transition to an adult service (4%) and information about financial issues (3%).

**Table 26** Information that could assist young people to make the transition

Type of transition information	Age group %		Total
	14–17	18–24	
Specialists & services in my area	31	45	38
What to expect (from the transition)	35	27	31
Differences between services	23	11	17
General information & support	13	14	14
Brochures	7	8	8
When to make the transition	4	3	4
Financial support & advice	3	4	3
Other	3	3	3

Base: Respondents suggesting preferred information source (14–17 year olds: n= 163; 18–24 year olds: n=154).

### 5.3 Transition experiences

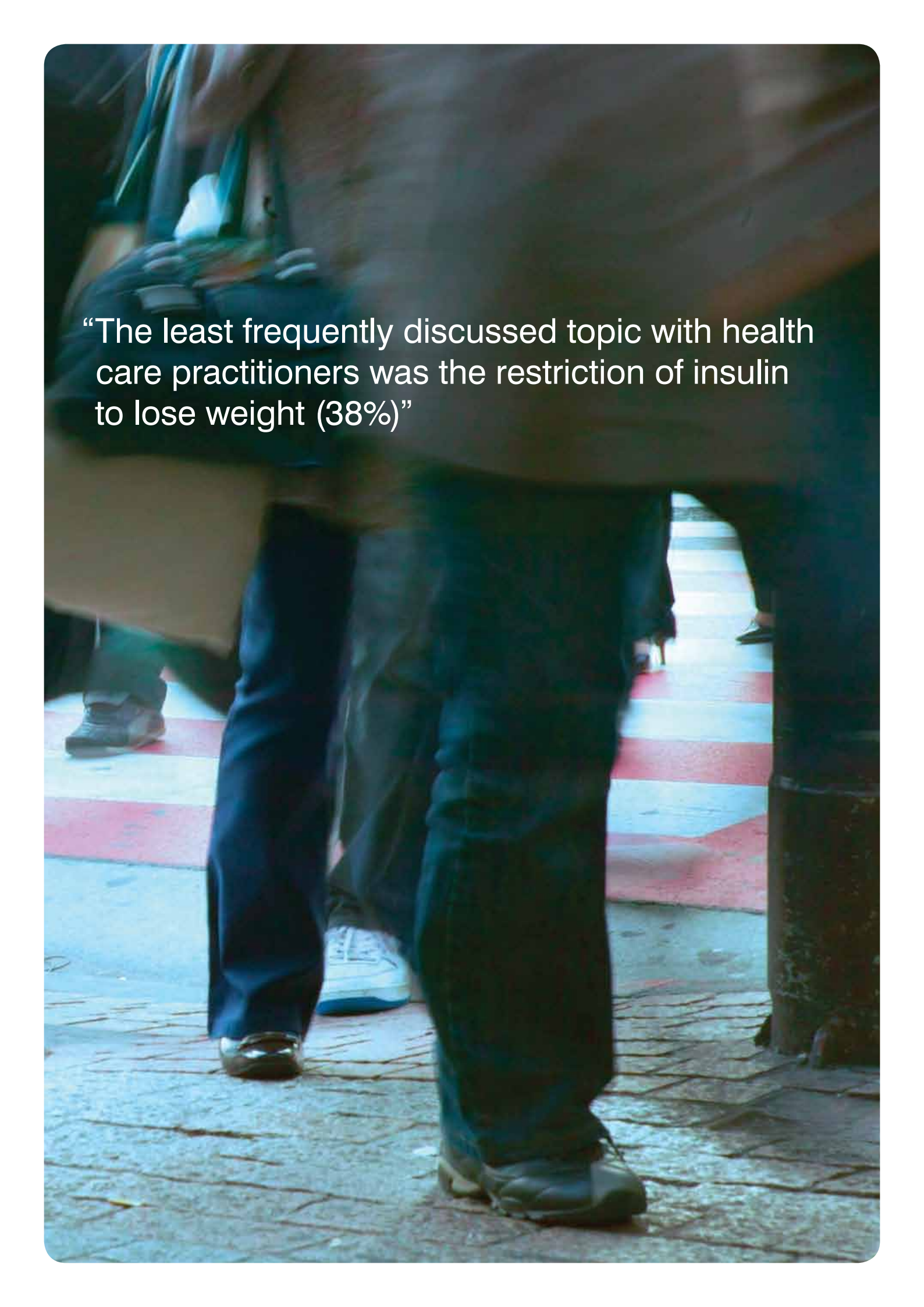
Seventy-eight percent of young people who were currently attending an adult service had made the transition to this service from a paediatric or YADS clinic. On average, these respondents were 18 years old when they transitioned to an adult service. Of the 87 young people who transferred to an adult clinic from another clinic, 62 percent said that someone had helped them to prepare to make the change. Table 27 lists the people and services that were most frequently reported as assisting young people to make the transition to an adult service. Diabetes nurse educators were mentioned most often (35%) as supporting the transition process with endocrinologists (33%), general practitioners (27%) and family members (19%) also reported as having assisted the young person to make the transition. Diabetes camps and the NDSS were never offered as having assisted with the transition.

**Table 27** Person who supported transition to an adult service

Support person	%
Diabetes Nurse Educator	35
Endocrinologist	33
General Practitioner	27
Family members	19
Other health care professional	8
Mental health professional	2
Peers with diabetes	2
Diabetes Australia	2
Diabetes camps	0
NDSS	0
Other	6
Can't recall	2

Base: Respondents who had been assisted in their transition (n= 52).

When asked if they had experienced any problems when they made this transfer, only 15 percent (12 respondents) indicated that there had been some issues when they changed services. These 12 respondents provided general comments on these difficulties including taking responsibility for managing their own care and a perception that they were receiving an inferior level of service at the adult clinic.



“The least frequently discussed topic with health care practitioners was the restriction of insulin to lose weight (38%)”



## 6. Information about care and management

Table 28 shows that, in general, older respondents had experienced more discussions with health care professionals about their diabetes than younger respondents. Eighty-six percent of those aged 18 to 24 reported discussions with their health care practitioners about alcohol and diabetes and three quarters (75%) discussed smoking and diabetes. These topics were also reported by the 14 to 17 year olds as being discussed most frequently with health care professionals. Approximately half of the young people said that they had discussed mental health issues (51%), eating disorders (47%) and sexual health (47%) in the context of their diabetes. The least frequently discussed topic with health care practitioners was the restriction of insulin to lose weight (38%). Of the females who responded to the survey, only 69 percent of 18 to 24 year olds and 42 percent of 14 to 17 year olds indicated that they had spoken to a health professional about pregnancy and diabetes.

**Table 28** Issues discussed with health care professionals

	Age group %		
	14–17	18–24	Total
Alcohol and diabetes	65	86	78
Smoking and diabetes	51	75	66
Mental health and diabetes	48	53	51
Eating disorders and diabetes	46	48	47
Sexual health and diabetes	36	54	47
Restricting insulin use to lose weight	32	42	38

Base: All respondents (14–17 year olds: n= 544; 18–24 year olds: n=892).

It can be seen from Table 29 that the main issue of interest to young people overall relates to ways of reducing health care costs (70%) with slightly more 18 to 24 year olds (73%) expressing an interest in this issue than 14 to 17 year olds (66%). Travel and diabetes (67%), health complications (65%) and exercise and diabetes (60%) were also of interest across both age groups. Younger respondents seemed to be more interested in finding out information about issues in general, with alcohol and diabetes (61%) being a key concern for 14 to 17 year olds. Sixty percent of females expressed an interest in finding out more about pregnancy and diabetes.

**Table 29** Issues of interest

	Age group %		
	14–17	18–24	Total
Ways of reducing your health care costs	66	73	70
Travel and diabetes	70	65	67
Health complications	71	61	65
Exercise and diabetes	67	56	60
Weight management and diabetes	60	53	55
Alcohol and diabetes	61	41	49
Sexual health and diabetes	55	46	49
Mental health and diabetes	51	43	46
Eating disorders and diabetes	40	29	33
Illegal drugs and diabetes	35	24	28
Smoking and diabetes	33	21	26

Base: All respondents (14–17 year olds: n= 544; 18–24 year olds: n=892).

## 6. Information about care and management (continued)

Most young people expressed a preference for receiving written information, such as flyers or booklets on request (81%) (see Table 30). Accessing information online via the NDSS website (74%) was also a popular option, as were e-newsletters (70%) with other online options such as via social networking (64%) or through a chat room (51%) being of less interest. Face-to-face methods of receiving information including one-on-one conversations (69%) and information forums (68%) were more frequently mentioned as preferred methods of receiving information.

**Table 30 Preferred method of receiving information**

	Age group %		
	14–17	18–24	Total
Written material available on request	78	82	81
Online via the NDSS website	72	75	74
E-newsletters	68	71	70
One-on-one conversation with state or territory NDSS Agent	69	69	69
Information forums with health professionals on diabetes management	69	67	68
Online via social networking sites such as Facebook or Twitter	67	62	64
Face-to-face peer support groups	59	56	57
Online via a chat room or forum for young people with diabetes	51	50	51

Base: All respondents (14–17 year olds: n= 544; 18–24 year olds: n=892).

## 7. Transition liaison coordinators

The last section of the survey asked young people to consider the idea of a transition liaison coordinator. The following information about a transition liaison coordinator was shown or read to each respondent.

*Finally a few questions about what you think about a new idea to help young people with diabetes transfer to adult diabetes services. The idea is that a person called a transition liaison coordinator would be available over the phone or by email at any time you need information or help in transferring to an adult service. The transition liaison coordinator is assigned to each individual once the transition process has commenced and will support you in becoming your own effective lifelong case manager. For example, this person could inform you about the different options of care available, provide information or resources about diabetes care and refer you to other services that are available including support groups and health care professionals.*

As can be seen from Table 31 respondents were overwhelmingly positive about the concept of a transition liaison coordinator with 91 percent indicating that they were somewhat positive about this idea. Only three percent of 14 to 17 year olds and four percent of 18 to 24 years olds were somewhat or very negative about the idea of a transition liaison coordinator.

**Table 31** Positive or negative response to the idea of a Transition Liaison Coordinator

Transition liaison coordinator	Age group		Total
	14–17	18–24	
Feel positive	92	91	91
Feel negative	3	4	4

Base: All respondents (14–17 year olds: n= 544; 18–24 year olds: n=892).

Those who felt positively about the idea of a transition liaison coordinator were asked to comment on what they liked about the concept, as detailed in Table 32. Most indicated that it was good to have someone there (36%) and others liked that they had someone to contact (19%), that a transition liaison coordinator was better for the process (16%) or that it represented a more personalised approach to providing support (14%).

Of the 42 respondents who indicated that they were not positive about the idea of a transition liaison coordinator, most said that this service wasn't needed because they already had people who could help. Others indicated that they were independent and could make the transition by themselves and some said having a discussion with a transition liaison coordinator could be awkward or embarrassing.

**Table 32** Positive views of a transition liaison coordinator

Positive about transition liaison coordinators	Age group %		Total
	14–17	18–24	
Good to have someone there	33	38	36
Being able to contact somebody	20	18	19
Informative	21	18	19
Better for the process	14	17	16
Personalised approach	13	14	14
Helpful	9	7	8
Other	12	16	14

Base: Respondents feeling positive about a transition liaison coordinator (14–17 year olds: n= 415; 18–24 year olds: n=742).

## 7. Transition liaison coordinators (continued)

Slightly more than three quarters (76%) of young people attending a paediatric or YADS clinic indicated that they would be either very or somewhat likely to use a transition liaison coordinator if one was available, with 33 percent of 18 to 24 year olds and 28 percent of 14 to 17 year olds saying that they were very likely (see Table 33).

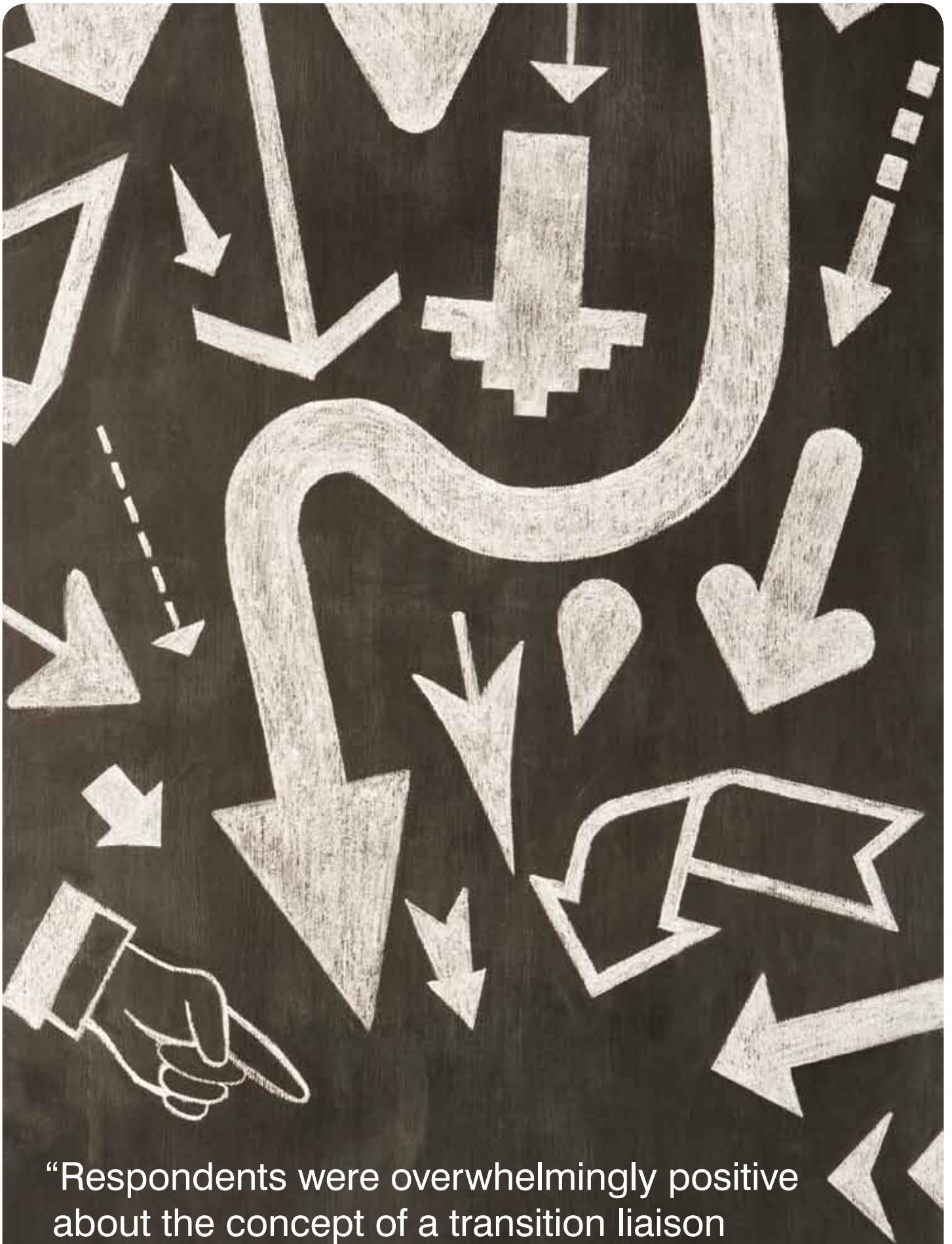
**Table 33** Likelihood of using a transition liaison coordinator

	Age group %		Total
	14–17	18–24	
Very likely	28	33	30
Somewhat likely	50	41	46
Neither	2	2	2
Somewhat unlikely	11	16	13
Very unlikely	2	5	3
Unsure	8	3	6

Base: Respondents attending a paediatric or a YADS clinic (14–17 year olds: n= 313; 18–24 year olds: n=244).

Young people who were attending a paediatric or a YADS clinic or had not seen a health professional in the last 12 months were asked if they would be willing to be contacted by a transition liaison coordinator. Young people aged 14 to 17 were slightly more positive (77%) than 18 to 24 year olds (73%) about being in touch with a transition liaison coordinator. Fourteen percent of young people were unsure about being contacted by a transition liaison coordinator.

Of the 87 young people who were currently attending an adult clinic, just over half (52%) felt that a transition liaison coordinator might have made their transition to this new service easier.



“Respondents were overwhelmingly positive about the concept of a transition liaison coordinator with 91 percent indicating that they were somewhat positive about this idea”

## 8. Young people disengaged from care

Three levels of disengagement from care were observed in the data. The first level of disengagement was from receiving care from specific professionals. In this case, some young people reported that there were health care professionals that they had never seen and a number of these practitioners were vital to the effective management of their condition. The second level of disengagement was evident in those young people who indicated that they were either not currently attending or had never attended a clinic to support their care. The smallest group, but most serious level of disengagement, were young people who did not appear to be engaging with the health care system at all, other than to fulfil the most basic aspects of managing their condition. Each of these disengaged groups is discussed below.

### 8.1 Health care professionals never seen by young people

Table 34 shows which health care professionals young people with diabetes are most likely to report never having seen as part of their treatment regimen. Alternate or complementary therapists had never been seen by 88 percent of young people, irrespective of their age group or clinic attendance. Of more concern is the observation that 62 percent reported they had never seen a podiatrist. Those who were aged 18 to 24 (69%) or never attended a clinic (71%) were more likely to indicate that they had never been to a podiatrist. Two in five respondents believed that they had never seen a dentist (41%) or a mental health professional (41%) and there were no substantive differences in terms of age of respondent or clinic attendance.

**Table 34 Health care professionals never seen**

Health care professionals	Age group			Attended clinic		
	14–17	18–24	Total	Yes	No	Total
<b>All respondents</b>	<b>544</b>	<b>892</b>	<b>1,436</b>	<b>761</b>	<b>624</b>	<b>1,385</b>
Alternate therapist	87	88	88	87	89	88
Podiatrist	52	69	62	54	71	62
Dentist	44	40	41	41	41	41
Mental health professional	42	40	41	39	44	41
Paediatrician or physician	18	30	26	21	31	26
Eye specialist	20	10	14	14	14	14
General practitioner	11	8	9	10	8	9
Dietitian	4	10	8	5	11	8
Endocrinologist	9	5	7	5	9	7
Diabetes nurse educator	2	5	4	2	6	4

Note: Multiple response question, respondents were able to select more than one health care professional.

The data in Table 34 also suggests that comparatively small, but notable, proportions of young people with diabetes said that they had never seen an eye specialist (14%), a general practitioner (9%), a dietitian (8%) or an endocrinologist (7%). There are a number of possible explanations for young people indicating that they had never seen key health professionals, aside from them actually never accessing these practitioners or services. Some respondents may have forgotten that they had seen these health professionals, particularly if the appointment was more than six months ago. It is also possible that some of the young people surveyed did not differentiate between the various practitioners they saw at a clinic or that did not know the formal names of the medical specialisations involved in their care. Appendix 2 contains additional information where respondents were unsure if they had seen specific health care professionals. It is possible that the five percent of young people who were unsure if they had ever seen an endocrinologist (see Appendix 2) should be combined with the seven percent who reported that they had never seen an endocrinologist to provide a more complete picture of those who are highly disengaged or very unclear about how diabetes is managed effectively.

### 8.2 Clinic non-attendance

Fifteen percent of young people who were no longer attending a clinic, but had attended a clinic in the past were unsure why they were not currently using a clinic. More specific reasons for not attending a clinic are provided in Table 35. The most common explanation for not currently attending a clinic was that the young person was now receiving private health care (25%), inconvenient hours (20%), poor service (18%) and inconvenient location (15%). A greater proportion of 18 to 24 year olds (14%) than 14 to 17 year olds (4%) reported that they were not attending a clinic because of their age. Seventeen percent of young people indicated that they had no need to attend a clinic, but didn't provide any further information about why they had no need to attend, with similar proportions of 14 to 17 and 18 to 24 year olds indicating that this was the case.

**Table 35 Not currently attending a clinic but have done so in the past**

Reason for not currently attending	Age group %		Total
	14–17	18–24	
Changed to private health care	31	23	25
Inconvenient hours	20	20	20
Poor service	22	18	18
No need	16	17	17
Inconvenient location	16	14	15
Because of age	4	14	12
Other	6	8	7

Base: Respondents who previously attended but are not currently attending a clinic (14–17 year olds: n= 63; 18–24 year olds: n=240).  
 Note: Multiple response question, respondents were able provide more than one reason.

Of the 675 young people who were not currently attending a clinic, 47 percent said that they had never attended a paediatric, YADS or adult clinic. Forty nine percent of young people aged 14 to 17 and 28 percent of those aged 18 to 24 were unsure why they had never attended a clinic. When asked why they had never attended a clinic most indicated that they didn't need to attend (40%) or that they didn't know about the clinics (30%) (see Table 36). Fewer reported that they were too busy to attend a clinic (13%) or that there were no clinics where they lived (12%).

**Table 36 Never attended a clinic**

Reason for never attending	Age group %		Total
	14–17	18–24	
I don't need to	54	37	40
I didn't know about them	21	32	30
Too busy	4	14	13
None in my area	14	12	12
Other	7	10	10

Base: Respondents who have never attended a clinic (14–17 year olds: n= 28; 18–24 year olds: n=161).  
 Note: Multiple response question, respondents were able provide more than one reason. Very small sample size for 14–17 year olds, results should be interpreted with caution.

### 8.3 Failure to engage with the health care system

Sixteen respondents (three 14 to 17 year olds and thirteen 18 to 24 year olds) indicated that they were not attending a clinic and had not seen a general practitioner, endocrinologist or a diabetes nurse educator in the past 12 months. Ten had seen a health care professional about their diabetes in the past one to two years and the other six respondents had not seen someone about their diabetes for three or more years.

Four respondents indicated that they were unsure why they had not seen a health care professional about their diabetes in the past 12 months. Reasons provided by the other young people for not seeing someone about their diabetes centered around being too busy or not having the time with others suggesting that the distance they were required to travel was a barrier to engaging with the health care system about their condition.

When asked where they were getting insulin prescriptions from, eight reported that they were receiving prescriptions from a general practitioner. As it is unlikely that a general practitioner would have provided prescriptions to cover a 12 month period, it could be possible that these young people are seeing a general practitioner just to get a script but are not seeing the same practitioner regularly or are not engaging with them about any other aspect of managing their diabetes.

Of the six young people who were totally disengaged from the health care system, and had not been to a clinic or seen any health care professional in the past 12 months, three said that they would return to treatment if a transition liaison coordinator was available to help them.

## 9. Conclusions and Recommendations

### 9.1 Preventing disengagement

While around two-thirds of young people were appropriately engaged with health care practitioners, approximately one third reported that they had an irregular pattern of contact with general practitioners or endocrinologists. This finding was surprising given that the majority of younger people with diabetes attend medical appointments with a parent or guardian and, as such, are likely to be seeing the relevant practitioners on a regular basis. If it is the case that these younger people are seeing these practitioners but do not necessarily understand who they are and the role that they play in the care of their diabetes, it is concerning that parents may not be ensuring that their children are engaged in their own care and comprehend who they are seeing to help manage their diabetes.

#### Recommendation

The NDSS to establish a breakdown of terminology to help people with diabetes clearly understand all of the services available to them and be made available on the My-D youth website. Terminology should be used clearly and consistently by health practitioners (eg if the appointment is with an endocrinologist, the term 'doctor' should not be used).

It should be noted that there is an implicit assumption that all parents fully understand the care that their child is receiving and the importance of managing their child's condition. It may be the case that some parents do not fully understand how various health practitioners contribute to the care of their child with diabetes or that they do not encourage appropriate behaviors due to the potential tension this creates with their child. As young people with diabetes regard their parents as the most important people in their diabetes care, it is vital that parents are well educated and informed.

#### Recommendation

Investigate parents' understanding of the progression and management of diabetes from childhood to adolescence to ensure that they are actively supporting engagement.

### 9.2 Supporting engagement

As a substantial proportion of young people have never spoken about transitioning, an appropriate approach needs to be developed to support discussions about transitioning between the patient, their family and health care professionals. By doing so this could alleviate some of the initial fears of transitioning that might exist due to lack of patient knowledge on the subject.

A Transition Care Plan could form the framework for initiating and sustaining discussions around current and future care. This plan would consist of a more open dialogue between each patient's medical support team,

which includes the paediatrician, endocrinologist, diabetes educator and GP. A Transition Care Plan could help facilitate engagement as the health care support team would have a coordinated approach to working as a whole rather than providing care as a collection of individuals.

#### Recommendation

Provide every young person going through transition with a formal Transition Care Plan.

Young people with diabetes reported a range of needs regarding information on diabetes-related issues. These issues included relevant health complications, reducing health care costs, travelling with diabetes and alcohol and drugs. These resources should be made available through the My-D website and the NDSS website. There was also an indication that hardcopy materials are regarded as useful resources.

#### Recommendation

Through the NDSS National Development Program, develop and improve resource materials focusing on issues of interest outlined in section six of this report.

The concept of a transition liaison coordinator was explained to young people and the response to this type of support was overwhelmingly positive. Many young people with diabetes who had successfully made the transition thought that a transition liaison coordinator might have made their transition easier. A transition liaison coordinator could be responsible for the development and implementation of the Transition Care Plan as well as the dissemination of relevant information materials.

#### Recommendation

The NDSS continue to explore the potential role and usefulness of transition liaison coordinators through further research and funding.

### 9.3 Understanding support needs and the transition process

The research report documents the first step towards a better understanding of the support needs of young people with diabetes and the process as they transition from paediatric to adult services. As the report is a 'snapshot' of the current situation in Victoria and Tasmania, it is unclear whether these findings are equally applicable to young people with diabetes, their families and health care practitioners in other locations in Australia.

#### Recommendation

Diabetes Australia to conduct a national survey.



# Appendix 1: Demographic profiles

Table A1 Young people by age group

Respondent characteristics	Age group			Distribution by age group		
	14–17	18–24	Total	14–17	18–24	Total
<b>All respondents</b>	<b>544</b>	<b>892</b>	<b>1,436</b>	<b>38</b>	<b>62</b>	<b>100</b>
<b>Indigenous status</b>						
Indigenous	3	2	5	1	0	0
Non-Indigenous	486	809	1,295	89	91	90
Not specified	55	81	136	10	9	9
<b>Location</b>						
Tasmania	54	66	120	10	7	8
Victoria	490	826	1,316	90	93	92
<b>Gender</b>						
Male	289	487	776	53	55	54
Female	255	405	660	47	45	46
<b>Household type</b>						
A person living alone	0	33	33	0	4	2
A couple with one or more children living at home	432	518	950	79	58	66
A single parent with one or more children at home	75	97	172	14	11	12
Non-related people sharing a house or apartment	1	78	79	0	9	6
A couple with no children	1	64	65	0	7	5
Some other type of household	34	99	133	6	11	9
Not stated	1	3	4	0	0	0
<b>If at home, lives with parent or guardian</b>						
Yes	506	599	1,105	100	97	98
No	1	16	17	0	3	2
Total at home	507	615	1,122	-	-	-
<b>Has own Medicare card (not parents' card)</b>						
Yes	87	492	579	16	55	40
No	311	387	698	57	43	49
Unsure or not stated	146	13	159	27	1	11
<b>Has Centrelink Health Care Card</b>						
Yes	380	416	796	70	47	55
No	95	462	557	17	52	39
Unsure	69	14	83	13	2	6
<b>Type of diabetes</b>						
Type 1	526	827	1,353	97	93	94
Type 2	18	65	83	3	7	6
<b>Age when first diagnosed with diabetes</b>						
Less than 1 year old	9	13	22	2	1	2
1 to less than 5 years old	105	142	247	19	16	17
5 to less than 10 years old	161	220	381	30	25	27
10 to less than 15 years old	239	275	514	44	31	36
15 to less than 20 years old	29	193	222	5	22	15
20 years or more	1	47	48	0	5	3
Unsure	0	2	2	0	0	0

# Appendix 1: Demographic profiles (continued)

Table A2 Young people by location

Respondent characteristics	State			Distribution by State		
	Tas	Vic	Total	Tas	Vic	Total
<b>All respondents</b>	<b>120</b>	<b>1,316</b>	<b>1,436</b>	<b>8</b>	<b>92</b>	<b>100</b>
Indigenous status						
<b>Indigenous</b>	<b>2</b>	<b>3</b>	<b>5</b>	<b>2</b>	<b>0</b>	<b>0</b>
Non-Indigenous	98	1,197	1,295	82	91	90
Not specified	20	116	136	17	9	9
<b>Gender</b>						
Male	61	715	776	51	54	54
Female	59	601	660	49	46	46
<b>Household type</b>						
A person living alone	4	29	33	3	2	2
A couple with one or more children living at home	71	879	950	59	67	66
A single parent with one or more children at home	16	156	172	13	12	12
Non-related people sharing a house or apartment	9	70	79	8	5	6
A couple with no children	8	57	65	7	4	5
Some other type of household	10	123	133	8	9	9
Not stated	2	2	4	2	0	0
<b>If at home, lives with parent or guardian</b>						
Yes	82	1,023	1,105	94	99	98
No	5	12	17	6	1	2
Total at home	87	1,035	1,122	-	-	-
<b>Has own Medicare card (not parents' card)</b>						
Yes	54	525	579	45	40	40
No	55	643	698	46	49	49
Unsure or not stated	11	148	159	9	11	11
<b>Has Centrelink health care card</b>						
Yes	73	723	796	61	55	55
No	44	513	557	37	39	39
Unsure	3	80	83	3	6	6
<b>Type of diabetes</b>						
Type 1	115	1,238	1,353	96	94	94
Type 2	5	78	83	4	6	6
<b>Age when first diagnosed with diabetes</b>						
Less than 1 year old	0	22	22	0	2	2
1 to less than 5 years old	21	226	247	18	17	17
5 to less than 10 years old	34	347	381	28	26	27
10 to less than 15 years old	43	471	514	36	36	36
15 to less than 20 years old	16	206	222	13	16	15
20 years or more	6	42	48	5	3	3
Unsure	0	2	2	0	0	0

Table A3 Young people by clinic attendance

Respondent characteristics	Attended clinic				Distribution by clinic attendance			
	Yes	No	Unsure	Total	Yes	No	Unsure	Total
<b>All respondents</b>	<b>761</b>	<b>624</b>	<b>51</b>	<b>1,436</b>	<b>53</b>	<b>43</b>	<b>4</b>	<b>100</b>
<b>Age group</b>								
14–17	384	133	27	544	50	21	53	38
18–24	377	491	24	892	50	79	47	62
<b>Indigenous status</b>								
Indigenous	3	1	1	5	0.4	0.2	2.0	0.3
Non-Indigenous	684	565	46	1,295	89.9	90.5	90.2	90.2
Not specified	74	58	4	136	9.7	9.3	7.8	9.5
<b>Location</b>								
Tasmania	84	32	4	120	11	5	8	8
Victoria	677	592	47	1,316	89	95	92	92
<b>Gender</b>								
Male	412	336	28	776	54	54	55	54
Female	349	288	23	660	46	46	45	46
<b>Household type</b>								
A person living alone	11	22	0	33	1	4	0	2
A couple with one or more children living at home	548	369	33	950	72	59	65	66
A single parent with one or more children at home	85	81	6	172	11	13	12	12
Non-related people sharing a house or apartment	28	48	3	79	4	8	6	6
A couple with no children	22	39	4	65	3	6	8	5
Some other type of household	64	64	5	133	8	10	10	9
Not stated	3	1	0	4	0	0	0	0
<b>If at home, lives with parent or guardian</b>								
Yes	627	441	37	1,105	99.1	98.0	94.9	98.5
No	6	9	2	17	0.9	2.0	5.1	1.5
Total at home	633	450	39	1,122	-	-	-	-
<b>Has own Medicare card (not parents' card)</b>								
Yes	252	307	20	579	33	49	39	40
No	395	279	24	698	52	45	47	49
Unsure or not stated	114	38	7	159	15	6	14	11
<b>Has Centrelink health care card</b>								
Yes	471	297	28	796	62	48	55	55
No	239	304	14	557	31	49	27	39
Unsure	51	23	9	83	7	4	18	6
<b>Type of diabetes</b>								
Type 1	740	563	50	1,353	97	90	98	94
Type 2	21	61	1	83	3	10	2	6
<b>Age when first diagnosed with diabetes</b>								
Less than 1 year old	12	10	0	22	2	2	0	2
1 to less than 5 years old	135	104	8	247	18	17	16	17
5 to less than 10 years old	228	137	16	381	30	22	31	27
10 to less than 15 years old	289	204	21	514	38	33	41	36
15 to less than 20 years old	79	138	5	222	10	22	10	15
20 years or more	17	30	1	48	2	5	2	3
Unsure	1	1	0	2	0	0	0	0

## Appendix 2: Health care professional usage

**Table A4** Health care professionals seen in the last three months

Health care professionals	Age group %			Attended clinic %		
	14–17	18–24	Total	Yes	No	Total
<b>All respondents</b>	<b>544</b>	<b>892</b>	<b>1,436</b>	<b>761</b>	<b>624</b>	<b>1,385</b>
General practitioner	45	52	49	45	54	49
Endocrinologist	61	51	55	64	43	54
Paediatrician or physician	40	16	25	31	17	25
Diabetes nurse educator	53	33	41	51	28	40
Dentist	14	13	13	12	15	14

**Table A5** Health care professionals seen in the last six months

Health care professionals	Age group %			Attended clinic %		
	14–17	18–24	Total	Yes	No	Total
<b>All respondents</b>	<b>544</b>	<b>892</b>	<b>1,436</b>	<b>761</b>	<b>624</b>	<b>1,385</b>
General practitioner	63	72	69	64	74	68
Endocrinologist	73	70	71	80	61	71
Paediatrician or physician	51	25	35	43	25	35
Diabetes nurse educator	73	49	58	69	43	57
Dentist	30	26	28	27	29	28

**Table A6** Health care professionals seen in the last 12 months

Health care professionals	Age group %			Attended clinic %		
	14–17	18–24	Total	Yes	No	Total
<b>All respondents</b>	<b>544</b>	<b>892</b>	<b>1,436</b>	<b>761</b>	<b>624</b>	<b>1,385</b>
General practitioner	71	80	77	73	82	77
Endocrinologist	78	80	79	85	72	79
Paediatrician or physician	57	33	42	50	33	42
Diabetes nurse educator	83	62	69	81	56	69
Dentist	41	38	39	37	41	39
Dietitian	63	42	50	58	39	50
Mental health professional	30	28	29	31	26	29
Podiatrist	26	12	17	23	11	18
Eye specialist	57	65	62	63	61	62
Alternate therapist	4	5	5	5	4	5

**Table A7** Health care professionals seen more than 12 months ago

Health care professionals	Age group %			Attended clinic %		
	14–17	18–24	Total	Yes	No	Total
<b>All respondents</b>	<b>544</b>	<b>892</b>	<b>1,436</b>	<b>761</b>	<b>624</b>	<b>1,385</b>
General practitioner	13	10	11	13	9	12
Endocrinologist	5	12	9	5	15	9
Paediatrician or physician	9	23	18	14	24	18
Diabetes nurse educator	11	31	23	15	35	24
Dentist	11	20	17	18	15	17
Dietitian	32	48	42	36	50	42
Mental health professional	22	29	26	27	27	27
Podiatrist	20	17	18	20	16	19
Eye specialist	22	25	24	23	26	24
Alternate therapist	6	5	5	5	5	5







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